# ANNUAL REPORT 2002

# DIVISION OF DEVELOPMENTAL SERVICES



DIVISION OF DEVELOPMENTAL SERVICES

DEPARTMENT OF DEVELOPMENTAL AND

MENTAL HEALTH SERVICES

AGENCY OF HUMAN SERVICES

STATE OF VERMONT

JANUARY 2002

## Annual Report 2002

## **Division of Developmental Services**

## Division of Developmental Services Department of Developmental and Mental Health Services Agency of Human Services State of Vermont

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January 2002

The Division of Developmental Services would like to acknowledge the efforts of the developmental service providers who supplied much of the necessary information for this report.



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#### **HIGHLIGHTS FROM FY 2001**

#### Did you know?

- People getting family support represent 43% of all people served.
- The number of people who get supports that live with their family went up by 16% since FY '00.
- Thirty-five percent (35%) of people who receive home and community-based waiver services live with their family.
- The number of children (under age 22) who get supports went up by 17% since FY '00. Of the children who get support, 14% are age 6 and under, 66% are age 7 18, and 20% are age 19 21.
- Of the 308 children (ages 0-18) receiving home and community-based waiver services, 80% live at home with their family, 11% are in SRS custody, and 9% live with their family part time and/or with a home provider.
- Vermont is ranked #1 in the nation in the number of people with developmental disabilities who receive supported employment to work per 100,000 of the state population.
- The number of people receiving residential services in Vermont is virtually the same as in FY '00.
- The number of people who receive supported employment services has gone up each year since the change in the federal statute removing the institutional criteria for receiving Medicaid waiver-funded supported employment.
- In Vermont, the percentage of people with developmental disabilities who live in nursing homes has dropped for the 4<sup>th</sup> year in a row. Conversely, the percent of people with developmental disabilities in nursing homes nationally is on the rise.

## THOUGHTS ON SELF-DETERMINATION BY LARRY BISSONNETTE

Taking coats of mastery of lives of told what to do for most of their lives people off and putting on shirts of listeners to voices that make their ideas known if a path is found for them to travel freely down.

September 2001 Independent Service Broker Training Presentation



#### **INTRODUCTION**

The Vermont system of supports for people with developmental disabilities must be challenged to be as creative and free from barriers to individual independence as it possibly can. What is included in this annual report on the status of supports and services is a compilation of numbers, graphs, and information bits. They only show a small piece of the true fabric and richness of Vermont's supports for people with developmental disabilities. The following story of Ernest and George Catchapaw show how interdependence, grown out of a caring and creative developmental service system combined with committed members of one's own community and respect for choice and independence, can help two men achieve their dreams <sup>1</sup>.

#### The Story of Ernest & George Catchapaw

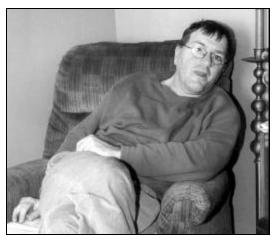
Ernest (46) and George (67) Catchapaw live in their own home in Cornwall. They moved there with their parents in 1952 from "the hollow" in Ferrisburg. After their mother's death last spring, funding was made available so that Ernest and George could remain in their home, with daily support. While Mrs. Catchapaw had been ill, she had personal care workers who came daily to help her. Ernest and George became close to the in-home aides, and wanted both of them to stay and help them to remain in Cornwall. It has been a community effort of good friends and family, close neighbors and committed support care workers who have enabled Ernest and George to live and thrive in their own home.

Ernest went to school, but George didn't. He stayed home and helped around the house. We moved here and then our father died in '66, when Ernest was 11. Our mother and our uncle took care of the cows. We kept going without help. Our barn burned down and we moved the cows to the farm down the road. We didn't have animals after the barn burned. We had a house burn down too. No one was hurt. It might have been 1980. The inside burned. We talked to the fire department and they burnt it down. It wasn't safe and we couldn't fix it.

Our mother had a garden. We helped inside, both of us. George did the cooking. Ernest mowed the lawn. We did more when she couldn't. Colleen [Champlain Valley Agency on Aging] came and visited our mother and us. She helped out. She got us a new rug. She helped us in the house. She got some people to come and help us. She got us help when our mother got sick. George helped take care of our mother when she got sick. He got up in the night when she called him.

People came in and helped us. They took us to town. Sometimes we'd go shopping. We used to go to see Tim [doctor] with Joan [guardian] and George knows the shortcuts. One time we were almost in New York.

<sup>&</sup>lt;sup>1</sup> All personal stories in this report have been edited to fit the space and for ease of reading.



Ernest Catchapaw

We got good neighbors. Paul and Debbie live next door. They know our mother and they came and visited her. They are on the Lifeline. Ernest goes to their garage to visit Paul.

We see our cousins now. We go visit them and they come here. Before she died, our mother said she wanted to stay at home with us and she did. When she died, we said we wanted to stay here. We told Joan and now Joyce and Ethel [support workers] help us. Things

are okay. We see our cousins in Barre and they sent us a Christmas present. We went there for Thanksgiving. We see our cousins in Addison. Our cousin helped us get a different dryer after the other one broke.

Jacob [Community Associates] helped with the bathroom. He's good. They have to put in another grab bar. Jacob plays drums too. We go shopping with Joyce at the A&P. George goes there because there's a place to sit down and pushes the cart at Ames instead of using the walker.

We like having help. Ethel and Joyce help. They take us out. We tell them what we want and they listen. George cooks breakfast, Joyce cooks lunch and Ethel cooks supper. Remember that pie she made? We like to go to the cooking classes. We'll go again. We took pictures at our cousin's in Barre and we got them developed. We went to the photography class too.

We do the laundry, but we won't do yours. We take the clothes out of the dryer fast. We always did our laundry here. We got a new mailbox and they're going to put the new mailbox in for us. Ethel gave us a new TV last year. We have a satellite dish and Joyce and her husband gave us the VCR for Christmas.

We have the Lifeline. We try to wear the Lifeline. Sometimes it bothers us to wear it. We'll wear it today after Joyce leaves. We have time by ourselves, not somebody here every minute. They're here enough. We think things are okay.



George Catchapaw

## **ATTACHMENTS**

#### DIVISION OF DEVELOPMENTAL SERVICES FY 2001 BUDGET

The Division of Developmental Services' appropriated budget for FY 2001 is \$74,180,880 (combined state general fund and federal Medicaid funds). This is allocated as follows:

Existing Community Services \$6	
5.7% Cost of Living Increase for Community Services	3,958,178
New Funding for Consumer Needs	
PDD Children (150,000 GF)	398,512
Emergency Caseload Increase (850,000 GF)	2,258,236
Flexible Family Funding (all GF)	80,000
June Graduates (75,000 GF)	199,256
Self-determination (200,000 GF – one time)	400,000
Division of Rate Setting	63,855
Salaries and Expenses for Guardianship Services	
and Division Administration	2,898,899

TOTAL \$74,180,880

## DIVISION OF DEVELOPMENTAL SERVICES ACRONYMS

AAC	Augmentative and Alternative Communication		
AAMR	American Association on Mental Retardation		
ACT 248	Supervision of incompetent and mentally retarded individuals		
ADD	Attention Deficit Disorder		
AFL	Authorized Funding Limit		
AHS	Agency of Human Services		
ANCOR	American Network of Community Options & Resources		
APS	Adult Protective Services		
APSE	Association for Persons in Supported Employment		
ARC	Advocacy, Resources and Community (formerly The Association of Retarded Citizens)		
ARIS	Area Resources for Individualized Services		
AT	Assistive Technology		
BTS	Brandon Training School		
CA	Community Associates (DS Program of CSAC)		
CAP	Community Access Program (DS program of RMHS)		
CARC	Champlain ARC – see ARC		
CAS	Community Alternatives Specialist		
CDS	Community Developmental Services (DS program of WCMHS)		
CIP	Core Indicators Project		
CIR	Critical Incident Report		
CP	Cerebral palsy		
CP	Certified Provider		
CPS	Child Protective Services		
CSAC	Counseling Service of Addison County		
CSHN	Children with Special Health Needs		
CVARC	Central Vermont ARC – see ARC		
CVS	Champlain Vocational Services		
DA	Designated Agency		
DAD	Department of Aging and Disabilities		
DBT	Dialectical Behavioral Therapy		
DD	Developmental Disability or Developmentally Disabled		
DD ACT	Developmental Disability Act of 1996		
DDC	Developmental Disabilities Council		
DDLP	Developmental Disabilities Law Project – Obsolete, see DLP		
DDMHS	Department of Developmental and Mental Health Services		
DDS	Division of Developmental Services		
DH	Developmental Homes – see also SLP		
DLP	Disability Law Project – formerly DDLP		
DMH	Division of Mental Health		
DOE	Department of Education		
DS	Developmental Services		
DSM	Diagnostic and Statistical Manual of Mental Disorders (most current edition)		
DSW	Department of Social Welfare – Obsolete, see PATH		
DVR	Division of Vocational Services – see also VR		

EDS Electronic Data Systems  FF Families First  FFF Flexible Family Funding  FFP Federal Financial Participation  FFS Fee for Service  FFY Federal Fiscal Year  FARC Franklin ARC – see ARC  F/GIMHS Franklin/Grand Isle Mental Health Services – Obsolete see NCSS  FY Fiscal Year  GF General Fund  GH Group Home  GMSA Green Mountain Self Advocates  GS Guardianship Services  GSS Guardianship Services Specialist  HCBS Home and Community-based Services  HOBW Home and Community-based Waiver	$\neg$
FFF Flexible Family Funding FFP Federal Financial Participation FFS Fee for Service FFY Federal Fiscal Year FARC Franklin ARC – see ARC F/GIMHS Franklin/Grand Isle Mental Health Services – Obsolete see NCSS FY Fiscal Year GF General Fund GH Group Home GMSA Green Mountain Self Advocates GS Guardianship Services GSS Guardianship Services Specialist HCBS Home and Community-based Services HCBW Home and Community-based Waiver	
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HCBW Home and Community-based Waiver	
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H-14- C Eigening Administration	
HCFA Health Care Financing Administration	
HCHS Howard Center for Human Services	
HCRS Health Care and Rehabilitation Services of Southeastern Vermont – See also HCRSSV	
HCRSSV Health Care and Rehabilitation Services of Southeastern Vermont	
HCS Howard Community Services (DS program of HCHS)	
HHS Health and Human Services	
HIPAA Health Insurance Portability and Accountability Act	
HRD Human Resources Data	
ICF/MR Intermediate Care Facility for people with Mental Retardation.	
IEP Individualized Education Program	
IPP Individual Program Plan – Obsolete, see ISA	
ISA Individual Support Agreement	
ISO Intermediary Service Organization	
LCMH       Lamoille County Mental Health         LIT       Local Interagency Team	
LIT Local Interagency Team  LSI Lincoln Street, Inc.	_
MCIS Managed Care Information System	
·	
MI Mentally Impaired/Ill MIS Management Information System	
MMPI Minnesota Multiphasic Personality Inventory	_
MR Mental Retardation	
MSR Monthly Service Report – formerly QSR	
NASDDDS National Association of State Directors of Developmental Disabilities Services	
NCSS Northwest Counseling and Support Services (formerly F/GIMHS)	
NKHS Northeast Kingdom Human Services (formerly NEKMHS)	-
NEKMHS Northeast Kingdom Mental Health Services – Obsolete, see NKHS	-
OT Occupational Therapy or Occupational Therapist	$\dashv$
P&A Protection and Advocacy – see VP&A	$\exists$
PASARR Pre-admission Screening and Resident Review	$\exists$
PATH Department of Prevention, Assistance, Transition and Health Access	$\exists$
PDD Pervasive Developmental Disorder	$\neg$
PMIS Provider Management Information System	
PT Physical Therapy or Physical Therapist	$\exists$
QA Quality Assurance	$\neg$

QDDP	Qualified Developmental Disabilities Professional		
QI	Quality Improvement		
QMRP	Qualified Mental Retardation Professional – see QDDP		
QSR	Quarterly Service Report – Obsolete, see MSR		
RACS	Rutland Area Community Services – Obsolete, see RMHS		
RARC	Rutland ARC – see ARC		
RCL	Resources for Community Living – Obsolete		
RMHS	Rutland Mental Health Services		
RWJ	Robert Wood Johnson Foundation		
SAP	Supervised Apartment Program		
SAS	Sterling Area Services		
SCC	Specialized Community Care		
SD	Self-determination		
SDP	Self-Determination Project		
SIT	State Interagency Team		
SLP	Shared living provider		
SLP	Speech language pathologist		
SRS	Department of Social and Rehabilitation Services		
SSA	Social Security Administration		
SSA	Specialized Service Agency		
SSDI	Social Security Disability Insurance		
SSI	Supplemental Security Insurance		
TASH	The Association for Persons with Severe Handicaps		
TBI	Traumatic Brain Injury		
TCM	Targeted Case Management (Medicaid)		
T-II	Transition II		
TXIX	Title XIX of the Social Security Act (Medicaid)		
UAP	University Affiliated Program		
UCS	United Counseling Service of Bennington County		
UIC	University of Illinois at Chicago		
UVS	Upper Valley Services		
VARC	ARC of Vermont– see ARC		
VCCMHS	Vermont Council of Community Mental Health Services – Obsolete, see VCDMHS		
VCDMHS	Vermont Council of Developmental & Mental Health Services – formerly VCCMHS		
VCDR	Vermont Coalition for Disability Rights		
VCIL	Vermont Center for Independent Living		
VCIN	Vermont Crisis Intervention Network		
VP&A	Vermont Protection and Advocacy		
VPIC	Vermont Parent Information Center		
VPS	Vermont Psychiatric Survivors		
VPSN	Vermont Peer Support Network – Obsolete, see GMSA		
VR	Vocational Rehabilitation – see also DVR		
VSH	Vermont State Hospital		
VSL	Vermont Supported Living		
UVM	University of Vermont		
WAIS-R	Wechsler Adult Intelligence Scale – Revised		
WCMH	Washington County Mental Health		
WISC	Wechsler Intelligence Scale for Children		

#### **DIVISION OF DEVELOPMENTAL SERVICES**

January 2002

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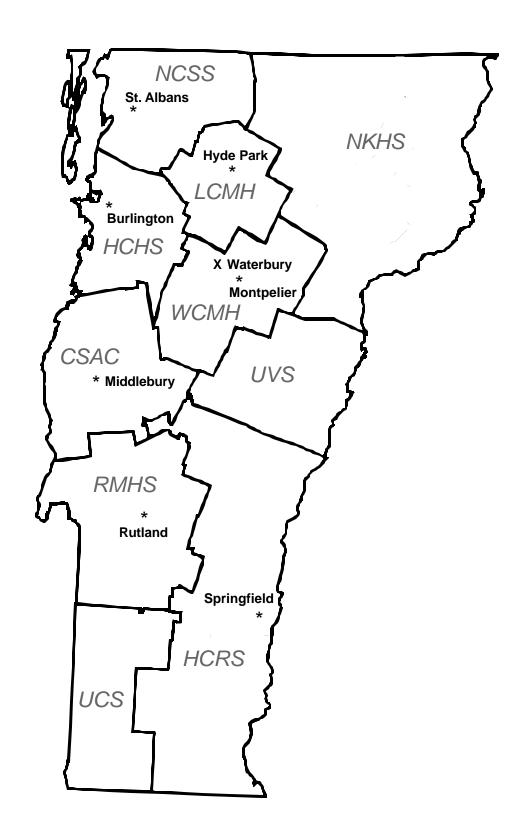
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## Division of Developmental Services Guardianship Services Offices



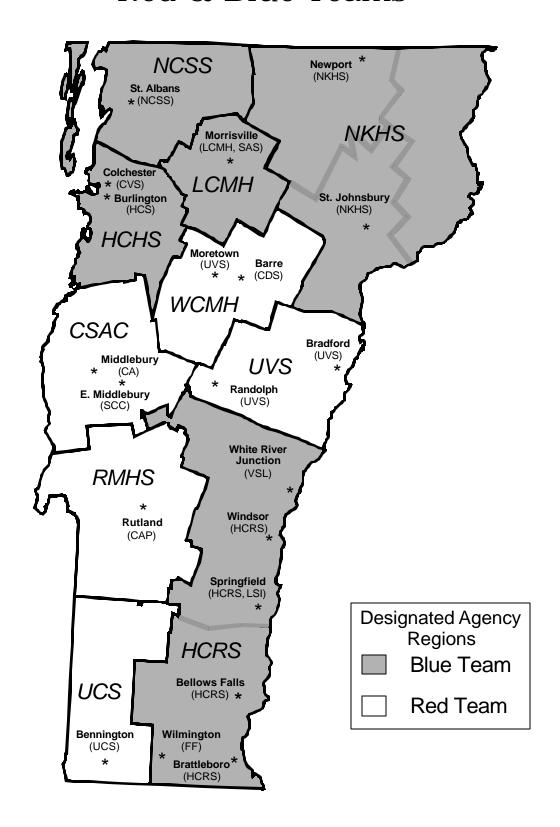
## Division of Developmental Services Blue and Red Team Structure

Blue Team			
Role	Staff Name	<b>Provider Contact</b>	
DS Team Leader	Bob Turchin	SCC	
Generalist	Martin Morse	HCRS, NEK, FF	
Children Specialist	Clare McFadden	HCS	
Employment Specialist	Chris O'Neill	CVS, LCMH	
Housing Specialist	Jim Cameron <sup>2</sup>		
Nursing Specialist	Maureen Rappeno		
Training Specialist	Avi Freund	NCSS	
Program Services Clerk	Marie Goslant		
Secretary	Erin Ward		

Red Team			
Role	Staff Name	Provider Contact	
DS Team Leader	Ellen Malone	CDS	
Generalist	Amy Roth	CAP, LSI, SAS	
Children Specialist	Janine Parker-Moulton	CA, VSL	
Employment Specialist	Jennie Kennedy	UCS	
Housing Specialist	Jim Cameron <sup>3</sup>		
Nursing Specialist	Kate Spencer		
Training Specialist	Jeff Coy	UVS	
Program Services Clerk	Marie Goslant		
Secretary	Erin Ward		

<sup>&</sup>lt;sup>2</sup> Contracted position shared between Red & Blue Teams. <sup>3</sup> Contracted position shared between Red & Blue Teams.

## Division of Developmental Services Red & Blue Teams



## DEVELOPMENTAL SERVICES STATE STANDING COMMITTEE MEMBERS

Name	Address, Phone & Fax	Represents	Term Expires (July 1)
Aichroth, Susan	104 Marsett Road Shelburne, VT 05482 Pager: 250-1714 Phone: 985-9035 e-mail: aichroths@aol.com	People with Developmental Disabilities	2004
Arsenault, Dawn	54 Jalbert Road Barre, VT 05641 Phone: 476-0624	Professional/Advocates	2004
Bakeman, Anne	3 Bedford Green South Burlington, VT 05403 Phone: 658-3374 Fax: 658-8061 e-mail: abakeman@zoo.uvm.edu	Family Members	2003
Breiden, Nancy	Disability Law Project 57 N. Main Street Rutland, VT 05701 Phone: 775-1122 Fax: 775-0022 e-mail: nbreiden@vtlegalaid.org	Professionals/Advocates	2003
Cameron, Margi	Howard Community Services 102 South Winooski Avenue Burlington, VT 05401 Phone: 658-1914 Fax: 860-2360 e-mail: margic@howardcenter.org	Professionals/Advocates	2003
Cheney, Karen	170 Centerview Terrace St. Johnsbury, VT 05819 Phone: 485-8271 Fax: 748-1447	Family Members	2003
Daniels, Martin	84 North Street Northfield, VT 05663 Phone: 485-8271 Fax: 485-4596	Family Members	2002
Hathaway, Sarah	6 Sabin Street Montpelier, VT 05602 Phone: 223-6480 e-mail: verelli@aol.com	People with Developmental Disabilities	2003
Milizia, Betty	ARC of Vermont 208 Colchester Avenue Burlington, VT 05401 Phone: 658-7419 (h) 658-2221 (w) Fax: 658-1557 e-mail: miliziaarc@aol.com	Professionals/Advocates	2004

Name	Address, Phone & Fax	Represents	Term Expires (July 1)
Morse, Janeen A.	14 Jacobs Drive #12 Randolph, VT 05060-1228 Phone: 728-3433 (h) 728-4476 (w) Fax: 728-6741 e-mail: road_runner@yahoo.com	Professional/Advocate	2002
O'Riordan, Kevin	Sterling Area Services, Inc. PO Box 1207 Morrisville, VT 05661 Phone: 888-7602 Fax: 888-1182 email: <a href="mailto:saskev@banet.net">saskev@banet.net</a>	Professionals/Advocates	2004
Place, Edwin	Randolph House Apt. 208 Main Street Randolph, VT 05060 Phone: 728-2021	People with Developmental Disabilities	2002
Stubbs, Sandra	ARIS, Inc. PO Box 4409 White River Jct., VT 05001 Phone: 295-1658 Car Phone: (603) 381-6087 Fax: 295-0663 e-mail: areares@together.net	Professional/Advocate	2002
Woodberry, Connie	103 Partridge Road East Dummerston, VT 05346 Phone: 257-0300 (h) 254-8611 (w) e-mail: conniewo@sover.net fax: 254-8611	Family Members	2001
Vacancy		People with Developmental Disabilities	2002

#### **VERMONT DEVELOPMENTAL SERVICES PROVIDERS**

January 2002

(CVS) CHAMPLAIN VOCATIONAL SERVICES, INC.

77 Hegeman Ave., Fort Ethan Allen Exec. Director: Paul Dicken

Colchester, VT 05446 County: Chittenden

Phone 655-0511 FAX: 655-5207

(CAP) COMMUNITY ACCESS PROGRAM OF RUTLAND COUNTY

PO Box 222, 1 Scale Avenue Director: Jerry Bernard

Rutland, VT 05701 County: Rutland

Phone: 775-0828 FAX: 747-7692

(CA) COMMUNITY ASSOCIATES

61 Court Street Director: Gregg Mousley

Middlebury, VT 05753 County: Addison

Phone: 388-4021 FAX: 388-1868

(CDS) COMMUNITY DEVELOPMENTAL SERVICES

50 Grandview Drive Director: Juliet Martin Barre, VT 05641 County: Washington

Phone: 479-2502 FAX: 479-4056

(HCRS) HEALTH CARE & REHABILITATION SERVICES OF SOUTHEASTERN VT

118 Park Street Director: Maryann Willson Springfield, VT 05156 Counties: Windsor & Windham

Phone: 885-5171 FAX: 885-5173

Regional Offices:

5 Fairview Street, Brattleboro, VT 05301 14 River Street, Windsor, VT 05089 Phone: 254-6028 FAX: 254-7501 Phone: 674-2539 FAX: 674-5419

PO Box 773, Bellows Falls, VT 05101 Phone: 463-3962 FAX: 463-3961

(HCS) HOWARD COMMUNITY SERVICES

102 South Winooski Ave. Director: Marie Zura Burlington, VT 05401-3832 County: Chittenden

Phone: 658-1914 FAX: 860-2360

(FF) FAMILIES FIRST

PO Box 939, Wilmington, VT 05363 Director: Julie Cunningham

Phone: 464-9633 FAX: 295-9107 County: Windham

(LCMH) LAMOILLE COUNTY MENTAL HEALTH SERVICES, INC.

520 Washington Highway Director: Brian Fagan Morrisville, VT 05661 County: Lamoille

Phone: 888-6627 FAX: 888-6393

(LSI) LINCOLN STREET INCORPORATED

PO Box 678 Executive Director: Cheryl Thrall

Springfield, VT 05156 County: Windsor

Phone: 885-9533 FAX: 885-9575

(NCSS) NORTHWESTERN COUNSELING & SUPPORT SERVICES, INC.

107 Fisher Pond Road Director: Jean Gilmond

St. Albans, VT 05478 Counties: Franklin & Grand Isle

Phone 524-6561 FAX: 527-8161

(NKHS) NORTHEAST KINGDOM HUMAN SERVICES, INC.

PO Box 724, 154 Duchess Street Director: Eric Grims

Newport, VT 05855 Counties: Caledonia, Orleans & Essex

Phone: 334-6744 FAX: 334-7455

Regional Office:

PO Box 368, 141 Railroad Street

St. Johnsbury, VT 05819

Phone: 748-3181 FAX: 747-7697

(SCC) SPECIALIZED COMMUNITY CARE

PO Box 578 Executive Director: Ray Hathaway East Middlebury, VT 05443 Counties: Addison & Rutland

Phone: 453-4175 FAX: 453-4809

(SAS) STERLING AREA SERVICES, INC.

PO Box 1207 Executive Director: Kevin O'Riordan

Morrisville, VT 05661 County: Lamoille

Phone: 888-7602 FAX: 888-1182

(UCS) UNITED COUNSELING SERVICES, INC.

PO Box 588, Ledge Hill Drive Director: Kathy Hamilton Bennington, VT 05201 County: Bennington

Phone: 442-5491 FAX: 442-3363

(UVS) UPPER VALLEY SERVICES, INC.

RR1, Box 76 Executive Director: William Ashe Bradford, VT 05033 Counties: Orange & Washington

Phone: 222-9235 FAX: 222-5864

Regional Offices:

12 Prince Street, Randolph, VT 05060 Po Box 719, Moretown, VT 05660 Phone: 728-4476 FAX: 728-6741 Phone: 496-7830 FAX: 496-7833

(VSL) VERMONT SUPPORTED LIVING

331 Olcott Drive, White River Jct. VT 05001 Director: Robert Vaillencourt

Phone: 295-9100 FAX: 295-9107 County: Windsor

#### **GREEN MOUNTAIN SELF-ADVOCATES**

January 2002

Green Mountain Self-Advocates (GMSA)
73 Main Street, Suite 401
Montpelier, VT 05602
802-229-2600
Contact: Lisa Smedy & Karen Topper

Toll Free: 1-800-564-9990

#### LOCAL CHAPTERS:

#### **Bellows Falls Support Group**

Health Care & Rehabilitation Svs. PO Box 773, 12 Church Street Bellows Falls, VT 05101 (802) 463-3962

#### **Bennington Peer Support**

United Counseling Services, Inc. PO Box 588 Bennington, VT 05201 (802) 442-5491 – Paula Colbert Board Rep: Holly Colvin

#### **Bradford Peer Support**

Upper Valley Services, Inc. RR 1, Box 76 Bradford, VT 05033 (802) 222-9235 – Lorraine Gaboriault

#### **Brattleboro Peer Support**

Health Care & Rehabilitation Svs. 230 Main Street, Suite302 Brattleboro, VT 05301 (802) 254-5537 – Lori Greenburg

#### **Burlington Peer Support**

Howard Community Services 102 South Winooski Ave. Burlington, VT 05401 (802) 658-1914 – Mark Ridderhoff Board Rep: Catherine Jones

#### **Champlain Voices**

Champlain Vocational Services, Inc. 77 Hedgeman Ave., Fort Ethan Allen Colchester, VT 05446 (802) 655-0571 – Linda Chaisson Board Rep: Paul Nichols

## Connections of Peer Support of White River Jct.

PO Box 678, Springfield, VT 05156 (802) 885-9533 – Karen Daley-Regan Board Rep: Paul Dunbar

#### **Friends Helping Friends**

Community Developmental Services 50 Grandview Drive Barre, VT 05641 (802) 479-2502 – Fran French Board Rep: Margaret Pearlstein

#### **HCRS Springfield Peer Support**

118 Park Street Springfield, VT 0515 (802) 885-5171 – Melissa Mullen

#### Lean on Me

Northeast Kingdom Human Svs., Inc. PO Box 368 St. Johnsbury, VT 05819 (802) 748-3181 Board Rep: Michelle Matteis

#### **Morrisville Peer Support**

PO Box 867 Morrisville, VT 05661 (802) 888-8407 Board Rep: Patty Grassette

#### **Next Step of St. Albans**

Northwestern Counseling & Support Services, Inc. 156 North Main Street St. Albans, VT 05478 (802) 524-6561 – Connie Farrington Board Rep: Heather Hendrick

#### **Our Drop In Center**

153 Main Street Newport, VT 05855 (802) 344-8378 Board Rep: Tammy Crowe

#### Randolph Area Peer Support

Upper Valley Services, Inc. 12 Prince Street, Suite #2 Randolph, VT 05060 (802) 728-4476 – Janeen Morse Board Rep: Ann Campbell

#### **Vermont Choices**

Northeast Kingdom Human Svs., Inc. PO Box 368 St. Johnsbury, VT 05819 (802) 748-3181 – Robin Burnash Board Rep: Duane Knight

#### Self-Advocates Becoming Empowered of Rutland

Rutland ARC 128 Merchants Row Rutland, VT 05701 (802) 775-1370 – Lisa Lynch Board Rep: Becky Hogdon

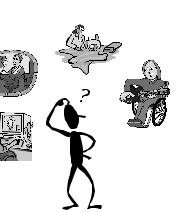
### Self Advocates Meeting of Springfield

PO Box 678 Springfield, VT 05156 (802) 885-9533 – Lori Jean Lintner Board Rep: Jean Martel

## GREEN MOUNTAIN SELF-ADVOCATES BILL OF RIGHTS

## DRAFT

The Right to schedule my own time, decide my own activities, and pick something else to do when plans have to change. determine alternate activities.





The right to choose
our own support staff and
be directly involved
in the hiring process.
This avoids total strangers walking
into our lives and taking over.

The right to communicate in the best way we can:



Spoken word
Touch talker
Facilitated Communication
Sign language Interpreter





Pictures
Written
Telephone / TTY
Body language
Bliss symbol

Gesture



GMSA Bill of Rights Page 2

The right to speak up when treated unfairly

People with disabilities in

Vermont have the right to information about trainings and self-advocacy.

We have the right to decide to attend the training or not, without being pressured.





The right to live in a safe home and be treated with respect.

Help me when needed and leave me alone when I can do it myself.

Free from physical harm, verbal abuse and swearing.

Respect all our boundaries

Make our own decisions and have them respected



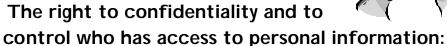


People should use good listening skills when being with us. Look at us and pay attention.

GMSA Bill of Rights Page 3

The right to privacy

The right to private time with a special person



files, case notes, personal shared information

Don't touch my stuff! Body privacy is respected





The right to choose where I live and who I live with.

The right to have relationships:

Friends

Relationships with our parents and family

Love relationships
Marriage
To be parents



We might need to learn about having relationships and sex Learning how to be safe, use condoms, birth control and about STD's sexually transmitted diseases. GMSA Bill of Rights Page 4

#### The right to a safe community



The right to be treated like everybody else and go out without being teased

Police training by people with disabilities on how to approach a person with a disability



The right to get a job if you want one.

The right to pick the job you want and to get the support you need to do the job.



The right to quit or look for a new job. We might need to go to school or get training on how to do a new job.

#### SOURCES OF QUALITY ASSURANCE AND PROTECTION FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES January 2002

Quality assurance activities will not be successful if they are relegated to a single bureaucratic cubbyhole. The Vermont developmental services system has numerous components that impact upon quality assurance. There is great value in having a multi-faceted system of quality assurance, and the participation of numerous people in quality promotion activities is a strength. In Vermont, the overall quality assurance system includes at least the following components:

#### I. Within the Department of Developmental and Mental Health Services:

- A. **Designation Process**. The Department of Developmental and Mental Health Services (DDMHS) designated one agency in each region of the state to ensure needed services are available through local planning, service coordination, and monitoring outcomes within their geographic region. The Designated Agency must either provide directly or contract with providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines.
- B. **Agency Reviews**. Twelve (12) full-time staff, including two registered nurses, conduct on-site reviews to assess the quality of services provided. The Community Alternative Specialist staff assess all Medicaid funded services to assure compliance with state and federal Medicaid standards and the outcomes detailed in the *Guidelines for Quality Services*. Site visits are conduced annually with follow-up as appropriate.
- C. Guardianship Services Specialists. Twenty (20) staff provide guardianship services as specified by law to about 580 adults with developmental disabilities. Guardianship Services Specialists play distinct quality assurance functions, including on-going monitoring of people's welfare, assessment of quality of life and functional accessibility, participation in individual support plans, and advocacy for appropriate services. Guardianship Services Specialists are expected to have face-to-face contact with people for whom they are guardian at least once a month.
- D. **Safety and Accessibility Checks**. All residences (except those licensed through the Department of Aging and Disabilities or a public housing entity, such as Section 8) funded by the Division of Developmental Services are inspected for compliance with safety and accessibility standards.
- E. Consumer & Family Surveys. The Division of Developmental Services contracts for independent statewide consumer interviews to take place on a regular basis to measure the satisfaction of people receiving services. A confidential family satisfaction mail-in survey is also conducted periodically to assess how families feel about services that they receive to support their family members who live at home.
- F. Critical Incident Reporting Process. Service providers provide critical incident reports to the Division of Developmental Services when certain incidents take place, such as the death of someone receiving services; use of restrictive procedures; allegations of abuse, neglect or exploitation; or criminal behavior by or against someone receiving services.

- G. Complaint and Appeals: Each service provider must have a written complaint and appeals procedure and inform applicants and service recipients of that process. Both informal and formal complaint and appeal processes are available to people applying for or receiving developmental services, their family members, guardians and other interested individuals.
- H. Ethics Committee. An Ethics Committee convenes bimonthly as needed, or on an emergency basis, to review any decisions by a Guardianship Services Specialist or other Division of Developmental Services staff to abate life-sustaining treatment for a person receiving services. In addition, any individual who wants advice about the ethical aspects of a decision, or is dissatisfied with a critical care decision made for a non-consenting person with developmental disabilities, may request the Ethics Committee to review the decision.
- I. Human Rights Committee. A Human Rights Committee meets monthly to review policies, procedures, trends and patterns, individual situations and positive behavior support plans to safeguard the human rights of Vermonters receiving developmental services. The committee provides an independent review of any restrictive procedures while assisting individuals and agencies to develop alternatives to restrictive procedures.

#### **II.** Elsewhere in State Government:

- A. **Residential Care Home Licensure**. The Department of Aging and Disabilities licenses residences where three or more unrelated people with disabilities live.
- B. Abuse Complaints. The Department of Social and Rehabilitation Services and the Department of Aging and Disabilities handle complaints of abuse and neglect for children and adults, respectively. Any human service worker, including Division of Developmental Services staff, is legally mandated to file an immediate report of any suspected abuse, neglect or exploitation of a person with a disability. For adults with disabilities, Adult Protective Services staff conducts independent investigations of each complaint and pursues legal or other recourse as indicated by the needs of the individual.
- C. **Fire Safety Regulation** Staff of the Department of Labor and Industry must approve all Level III Residential Care Homes and ICF/MR facilities. Facilities must meet appropriate standards of the National Fire Safety Code.
- D. **Vocational Rehabilitation (VR) Services**. Vocational rehabilitation services, (as opposed to Medicaid-funded work supports), are provided and reviewed by the Division of VR.
- E. Intermediate Care Facilities for People with Mental Retardation (ICF/MR). ICF/MRs are licensed and monitored under federally specified guidelines by nursing staff of the Division of Licensing and Protection, Department of Aging & Disabilities (DAD). The Division of Developmental Services conducts Utilization Reviews once every six months to determine whether continued stay is appropriate and necessary for each person residing in an ICF/MR.
- F. **Medicaid Fraud Unit**. This Unit investigates allegations of criminal activity, including abuse, neglect or exploitation, in any Medicaid-funded facility or involving a person receiving Medicaid-funded supports. The Medicaid Fraud Unit is a specially staffed unit within the Office of the Attorney General.

#### **III.** Within Developmental Services Agencies:

- A. The Individual's Circle of Support. Each person applying for or receiving services is encouraged to develop a circle of support. If they do not already have a circle, the service provider can help them form one. The circle is a group of people who helps the individual identify his/her dreams, takes responsibility to help the person create his/her plans and budgets, and determine the quality of his/her life. The primary focus of the circle is on the individual and what that person wants and needs. A circle of support is the ultimate safety net for that person.
- B. Local Standing Committee. Each designated agency and service provider has a local standing committee that is made up of at least 51% consumer and families, of which 25% must be direct consumers. The purpose of the Local Standing Committee is to involve people receiving services in planning and decision making regarding policies in order to increase consumer satisfaction, service and support quality, and organizational responsiveness. The committee submits a report to DDMHS annually.
- C. **Internal Mechanisms**. All agencies have some level of an ongoing quality improvement process as well as internal quality assurance, such as a Human Rights Committee, peer review, and Local Standing Committee oversight. The specific design and intensity of these efforts vary from agency to agency.
- D. **Service Coordination** Service coordination often includes the functions of "monitoring" and "advocacy." For some people, the service coordinator is the focal point for individual-based quality assurance at the local level.

#### **IV.** External to the Service System:

- A. **Developmental Services State Standing Committee**. The Developmental Services State Standing Committee was created by statute in 1990, (and updated through regulation in 1998), and is required to have at least 51% of its membership consumer and families. The Governor appoints this committee of people with disabilities, family members, advocates, and people with professional expertise in the field of developmental disabilities. It meets monthly as a working advisory group to the Division of Developmental Services.
- B. **Vermont Developmental Disabilities Council**. A broad-based, federally mandated board which provides independent oversight and systemic advocacy for the needs of people with developmental disabilities.
- C. **Protection and Advocacy System.** This system has two components: a legal component through the Disability Law Project (DLP) and citizen advocacy. The Disability Law Project is part of Vermont Legal Aid and has offices in Rutland, Burlington, Montpelier, Springfield and St. Johnsbury. They provide protection and advocacy services to individuals with disabilities in a wide variety of forums (e.g., court proceedings, school negotiations, administrative learings, Social Security Administration).

- D. **ARC of Vermont**. The ARC of Vermont provides a focus for families and concerned members of the public to identify and respond to the needs of people with developmental disabilities. There are four counties with local ARC offices. The Champlain ARC provides information, support and advocacy for individuals with disabilities and their family members in Chittenden County. Central Vermont ARC (Montpelier), Franklin ARC (St. Albans), and the Rutland ARC (Rutland) also share this mission.
- E. **Self-Advocacy**. The Green Mountain Self-Advocates, (formerly the Vermont Peer Support Network), a statewide self-advocacy group, works to empower people with disabilities to learn to make decisions, solve problems, speak for themselves, and to exert control over their own lives. It is committed to educating and making the general public aware of the strengths, rights and desires of people with disabilities. There are presently about 17 local chapters in various stages of development around the state.
- F. **Brandon Training School Association** An association of parents and other people concerned with the well being of former residents of Brandon Training School.
- G. Other Advocacy Groups. There are other locally based groups of concerned families and advocates. For example, Guardianship Trust provides regular, structured individually-based citizen monitoring of residential services provided by WCMH in Barre.
- H. Law Enforcement Agencies. In recent years, many local and state police have received training in the techniques of interviewing people with developmental disabilities who are victims of crime. The traditional sources of citizen law enforcement—the police, State's Attorney's, and Attorney General's offices—have played an increasingly effective role in protecting citizens with developmental disabilities who may become victims of crime.
- I. **Criminal Penalties.** Vermont law makes it a crime to abuse, neglect or exploit a person with a disability. The Office of Attorney General will prosecute for violations of this law.
- J. **The Federal Government.** Through Medicaid audits and look-behind surveys, the federal government provides a back-up system of quality assurance.
- K. Concerned Members of the Public. These include interested professionals (e.g., physicians, psychologists), members of the academic community, legislators, etc., who express their concerns through traditional channels of professional, administrative & legislative communication.
- L. **Above all, individual friends, family members, guardians, coworkers, neighbors**. Friends, family and neighbors provide for individuals in community settings the most important and dependable source of monitoring and advocacy someone that will "go to bat" for you if things are not going well.